



**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – December 6, 2010 (ratified)**

6pm – 9pm

**Location: Department of Human Services/Division of Developmental Disabilities
5 Commerce Way, Conference Room 199A, Hamilton, NJ**

Council Members Present

Elizabeth K. Bell, BS, volunteer and independent contractor with Autism Speaks,
Autism Organization Representative

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,
Assembly Speaker Appointee and Chair of Governor's Council for Medical Research and
Treatment of Autism

Susan P. Evans, EdD, Education Program Specialist for Early Intervention Program,
Commissioner of Health and Senior Services Appointee

Yvette Janvier, MD, FAAP, Medical Director for the Children's Specialized Hospital in Toms
River, Healthcare Organization Representative

Ketan Kansagra, MD, FAAP, Children's Hospital of New Jersey at Newark Beth Israel Medical
Center, Academic Institution Recommendation

Linda S. Meyer, EdD, MPA, BCBA-D Executive Director of Autism New Jersey, Autism
Organization Representative

Kendell R. Sprott, MD, JD, Acting Director of Pediatrics, University of Medicine and Dentistry-
New Jersey Medical School, Academic Institution Representative

Barbie Zimmerman-Bier, MD, Appointment at Rutgers University, clinician at St. Peter's
University, Academic Institution Representative

Absent

B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association,
Autism Organization Representative

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Grace M. Reilly, RN, MSN, APN-C, Adult Nurse Practitioner for Riverview Medical Center,
Individual with Autism or Family Member Representative

Judah Zeigler, Associate Vice President of Sharp's Retail and Consumer Marketing, Senate
President Appointee

NJ Department of Health and Senior Services (DHSS) Attendees

John Crosbie, Executive Director
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research
Commission on Spinal Cord Research

Cynthia Kirchner
Special Assistant to the Commissioner, DHSS
Ethics Liaison for the DHSS

Linda N. Bocclair, Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research
Commission on Spinal Cord Research

Lori Garg, MD, MPH, Senior Public Health Physician
Special Child Health and Early Intervention Services

General Public Attendees

Frank Costello, MD

Kathleen Freeman, PhD, RNC

Susan Freedman, Hunterdon Regional Autism Center and Special Child Health Services Case
Management

Audrey Mars, MD, Medical Director, Regional Autism Center at Hunterdon Medical Center

Walter Zahorodny, PhD, UMDNJ New Jersey Medical School

I. Welcome and Introductory Comments

The meeting was called to order at 6:15pm by Council Chair, Dr. Eggerding. Mr. Crosbie welcomed the Council and the public members. He also asked Council to join him in welcoming

Ms. Cynthia Kirchner, Special Assistant to the Commissioner and Ethics Liaison Officer for the DHSS, to the meeting.

II. Report of the Executive Director

Mr. Crosbie announced the following changes in staff and Council membership:

- Linda Bocclair, Executive Assistant to the Council, was hired in October. She is the “go to” person for Council business, with the task of keeping Council focused, organized and on track with accomplishing our responsibilities.
- Toni Tucker, who was the Administrative Assistant for the Brain Injury Commission, retired in December. She will be missed.
- Kathryn Simpson was hired as the secretary for the Council and the two Commissions (Brain Injury and Spinal Cord Injury). Kathryn is a welcome addition to the office and will frequently be the person who greets callers.
- Dr. Jessica Guberman resigned from the Council noting that she enjoyed working on the Council but as a result of commitments could not devote the time required to address and participate in Council business.
- Celeste Wood, Assistant Commissioner, DHSS retired in December. Gloria Rodriguez has assumed the position as Acting Assistant Commissioner.

Mr. Crosbie reported on the following:

The Memorandum of Agreement (MOA) with Rutgers University: Within the next couple of weeks Council will receive a survey from Dorothy Gaboda, PhD at the Center for State Health Policy at Rutgers University. The survey is an initial step in conducting a needs assessment of the autism research and services available in New Jersey, as specified in the MOA between Rutgers University and the NJDHSS. The purpose of the survey is to solicit information from members of the Council to help plan and conduct the project. Council’s cooperation in completing and returning the survey in a timely manner is greatly appreciated.

Program Monitoring:

(1) All six Principle Investigators (PIs) and their staff met at the DHSS offices on November 3, 2010. Following a brief business meeting, each of the PIs shared their Center’s accomplishments and challenges through PowerPoint presentations. The dialogue among representatives was very good with exchange of information on processes, procedures and strategies to address challenges. Center presentations will be scheduled for each of the next three Council meeting as a means of providing Council the opportunity to learn firsthand about the work of the Centers. Mr. Crosbie was excited and energized hearing what the Centers are doing and feels that Council will have a greater appreciation for the work that is being done at the Centers once members hear first hand from the Centers.

(2) In reference to the Year 2 Summary Reports from the Centers, Council is encouraged to contact either Mr. Crosbie or Ms. Bocclair with questions and/or suggestions. These reports are intended to provide Council with information about the accomplishments and challenges of the Centers, in a more condensed format than had previously been provided to Council. It was noted that the Center PIs were required to sign the cover sheet. Mr. Crosbie is trying to provide the essence of what the Centers are doing without burdening Council with the details. Mr. Crosbie welcomes Council feedback regarding the format of the reports. All suggestions are welcome. He is trying to make things accountable and transparent.

(3) Concerning the issue of accountability, a conference call was held on November 22 with the data coordinators at each of the Centers. While the Centers must be held accountable to provide meaningful data, there have been ongoing challenges in data collection. Any further delays in resolving issues with the collaborative database and in obtaining IRB and consent form approvals are unacceptable to Mr. Crosbie and to the Council. Centers must have IRB approvals by December 15 or a plan with timelines to obtain approval. Mr. Crosbie noted that in addition to problems at some of the Centers there are problems with the State in obtaining approval for the consent forms for the two Centers applying for IRB approval through the State IRB. Mr. Crosbie is close to resolving those problems and anticipates that all Centers will start data collection by January 3, 2011.

(4) With Center funding ending on June 30, 2011, Centers can request no cost extensions for unexpended funds, an option provided to any other grant funded program. Centers will provide a plan for up to a one year extension and will be required to submit quarterly reports and continue collecting data. Council will be notified of the dates for PI meetings with a request for RSVPs for those dates that members plan to attend the meetings (face-to-face and/or conference calls).

RFA Process: The RFA process is moving forward with meetings to clarifying issues and ensure consistency of format and intent between the Coordinating Center and Program Site RFAs. There have been numerous iterations and the RFAs are not yet complete. The RFA process is running parallel with our attempts to increase accountability and address challenges on a day-to-day basis. A priority has been to ensure accountability for those funds currently awarded to grantees. This is being done through grant monitoring and resolving collaborative database issues. What we learn now will inform how we move forward with the new system. A report confirming the distribution of the RFA funding (what will be funded and in what amounts) will be available to Council early to mid- January.

Scientific Advisory Committee (SAC): Mr. Crosbie is making headway and will accept names of potential committee members through Dec. 15. He has been contacting potential members referred to him by Council and will report at the next Council meeting. Some people he approached said “thanks but no thanks”. He blames, in part, the economy with people stretched beyond their limits and unable to accept additional responsibilities. To date, two candidates have expressed interest in serving and three have declined. The truth is that Mr. Crosbie has been busy with other responsibilities such as addressing issues with the existing Centers and moving the RFAs forward – it has just been a matter of priorities.

Annual Report: The 2009 Annual Report is posted on the Autism Council's website. The 2010 Annual Report is due by March 1.

Autism Council Website: Staff is working on website updates that should be completed by mid-January.

III. Approval of September 20, 2010 Minutes

Dr. Caroline Eggerding referred Council to an untitled document in their packets that listed changes, requested by Dr. Barbie Zimmerman-Bier, to the September 20, 2010 minutes. After a brief discussion a motion was made by Dr. Yvette Javier to accept the minutes with the changes and seconded by Ms. Elizabeth Bell. The Council voted unanimously to approve the minutes.

IV. Ethics Policy Training

Mr. Crosbie announced a change in the sequencing of agenda in that the next item on the agenda would be a presentation by the State Ethics Officer Margaret Cotoia. He welcomed Ms. Cotoia and Cynthia Kirchner, Special Assistant to the Commissioner and DHSS Ethics Liaison. Mr. Crosbie encouraged Council to participate in the interactive training as Margaret outlined the issues and Council's responsibilities. Ms. Kirchner addressed the Council stating that she is always available to Council at Cynthia.Kirchner@doh.state.nj.us or 609-984-0157 for any questions or concerns relating to ethical issues. She emphasized the importance for Council to truly understand ethics rules in which the Council operates. Members of the Governor's Council for Medical Research and Treatment of Autism are Special State Officers, as are members of all State Council and Commission, in their roles as Council members.

Ms. Cotoia from the New Jersey Commission on Ethics provided the membership with a presentation on the State of New Jersey's Ethics Policy. Members signed three documents certifying receipt of the Uniform Ethics Code, The Plain Language Guide to New Jersey's Executive Branch Ethics Standards, and Ethics training. Various issues involving Ethics were discussed and member questions were addressed. Special attention was paid to the area of recusals. Council members are considered special state officers and while they serve the State in a volunteer capacity, they are responsible to the public for their actions as a member of the Council. Their actions must be transparent to ensure public trust in the actions and decisions of the Council. If there is any question of conflict of interest, the member is encouraged to recuse meaning the member does not vote, is not present for the vote, and does not participate in any open or closed discussions. Members were reminded if they had any questions about recusals, or any other issues relating to Ethics, that they should contact Mr. Crosbie and he will arrange a call with Cynthia Kirchner. If members prefer they can contact Ms. Kirchner directly at Cynthia.Kirchner@doh.state.nj.us or 609-984-0157. Mr. Crosbie Thanked Ms. Cotoia for a most informative presentation.

V. Discussion following the Report of the Executive Director

Following the Ethics Training, Council discussed the following issues in response to the Executive Director's Report:

(1) In reference to program monitoring, one member commented that Year 2 Summary Reports should have asked the question “What was not accomplished during Year 2”.

(2) Two members commented with one questioning the number of employees (Council staff) servicing these grants (i.e. what is there in terms of oversight) and the second reminding Council that approval of the third year of funding was predicated on the understanding that program monitoring would be in place by the beginning of Year 3 and implemented throughout the year. Council needs transparency (i.e. what is happening and when). Council was under the impression that systems would be improved so that issues such as the collaborative database would be resolved in a timely manner. In reference to the database issues, the DHSS, not the Council, is ultimately responsible for reporting data accurately and completely. The Council is an advisory group.

(3) A question was raised regarding final reporting by the medical researchers who were funded by the Council in 2007. Until recently only two of the eleven researchers had submitted final reports. Mr. Crosbie indicated that five reports have been received with second reminders sent to the remaining seven in November. He indicated that the researchers may have sent the reports to the previous office staff but they may have been lost during the transition to the new staff. Researchers are not eligible for new grants if they have not fulfilled the reporting requirements of their previous grants. Council will receive a report listing the researchers and the status of reports. A question was raised regarding a requirement for the researchers to share their research. According to Attachment C of their NOGA researchers “Agree to participate in a collaborative conference sponsored by the Council, by presenting the innovative research conducted as a direct result of this funding initiative.”

(4) Council emphasized the importance of defining what matters in the RFAs and asking the right questions. There needs to be confidence in the applicant(s) ability to deliver what the Council has committed to fund.

(5) Council questioned the information that needs to be included in an annual report. Mr. Crosbie is interested in suggestions from the Council but the DHSS ultimately decides the format of annual reports.

(6) In response to the question of the current level of funding for the Centers and plans for future funding, Mr. Crosbie responded that the work of the Centers is very important but the purpose of the Council’s establishment of the NJ Autism Center of Excellence (NJACE), as outlined by the Statute, is not to be a service delivery system. The purpose is to create the NJACE with the new funding heavily weighted toward supporting high quality clinical research and treatment initiatives with emphasis on the coordination and dissemination of findings.

VII. Discussion of Remaining Agenda Items:

Budget

Mr. Crosbie noted that a State Senator's effort to take funding from the Council's to support the DHSS Early Intervention Program (EIP) was not approved; however, when the OMB was made aware of the funds, they encumbered the funds since at the time Council did not have a plan for spending the funds. Mr. Crosbie has discussed this issue with administration emphasizing that the Council has a five year plan and can only commit to implementing the plan with full assurance that all moneys currently committed and encumbered will be available to fund the plan.

The comment was made that if all funding is made available then \$2,000,000 should be committed to the development of a relational database since that level of funding is required and the proposal has been written. Mr. Crosbie encouraged Council to call their Senators and others to urge them to support our efforts to retain all of the funding allocated to Council including those encumbered by the OMB. While Mr. Crosbie is cautiously optimistic about the encumbered funds since state receipts are up and layoffs may not be necessary, he is aware that conditions could change.

A budget was presented for information only. It was decided that the budget was actually a report of revenue and expenditures and would be renamed for future reports. If there are any questions concerning the report, Council is encouraged to contact Mary Ray or Mr. Crosbie. The Report of Revenue and Expenditures will be sent to Council prior to Council meetings to ensure time for review.

Meeting Calendar

The Meeting Calendar for 2011 was distributed with a request for comments by December 15. If there are no comments, the calendar will be finalized and posted on the website. It was noted that the calendar is proposed and the title should indicate the same. The comment was made that the Council is required by the Rules of Order to meet only four times annually but they have chosen to meet more frequently. Mr. Crosbie emphasized the importance of members to attend all Council meetings especially since there are three vacancies and we need to hear from current members. The Governor's office has endeavored to fill vacancies – these are issues that Council has no control over. Some nominations are moving forward with the paperwork being prepared.

Ethical Responsibilities Document-Draft

The Ethical Responsibilities document was presented to Council with a request for members to review and be prepared to discuss and vote on at the next Council meeting. The approved document will be included in the Council's Rules of Order. Dr. Eggerding thanked Dr. Evans for composing the document. Dr. Evans noted that the document represents ethical behaviors and suggested adding it to the roles and responsibilities of Council as described in the Rules of Order. Mr. Crosbie noted that the document has been shared with the State Ethics Commission and since these are internal Rules they do not require Commission approval.

IX. Public Comments

Mr. Crosbie thanked the members of the public for their attendance and patience and asked for comments and/or questions.

In the spirit of transparency, Dr. Audrey Mars, Hunterdon Medical Center welcomed the Council to visit the Center. They have IRB approval and have been collecting patient data. They have submitted an application for approval of the addendum to their IRB in preparation for installation of the improved collaborative database in January.

Dr. Pnina Mintz, CNNH also welcomes visits from the Council and noted that a lot of work is being done, work beyond data collection. She reassured Council that there is communication and constant oversight and that Dr. Lori Garg is “staying on top of things”. The Centers are truly excited about what has been done at the Centers over the past two years and thanks on behalf of the CNNH, Dr. Mintz thanks Council for their support.

Dr. Kathleen Freedman requested that Council announce when training sessions would be held at meetings open to the public since she attends Council meetings to hear and respond to Council business. While ethics training is important, there was limited time following training to discuss the important business of the Council. Mr. Crosbie commented that ethics training updates will be held in the future with short presentations highlighting key issues.

Dr. Freedman commented that if Council were to attend PI meetings there would have to be a public notice of the meetings or Council attendance at the PI meetings would have to be limited to less than 50% of Council members.

X. Other Business

Mr. Crosbie encouraged Council to recruit individuals for consideration to serve on the Council. Applicants can apply to serve through the State website or directly to him.

The following comment was made regarding recusals: If a Council member chooses to recuse and the number of voting members falls below a quorum, the vote can be held. There is no need for a quorum for each vote. Further discussion/verification required and will be presented at the next Council meeting.

Mr. Crosbie announced that with two resignations, Council is now down three members. It is more important than ever for members to attend the meeting.

Mr. Crosbie announced that the Rules of Order require that the Council Chair is elected at the first meeting of the new year.

The next meeting of the Governor’s Council for Medical Research and Treatment of Autism is scheduled for February 7, 2011, 6pm – 9pm. Location to be determined.

XI. Adjournment The meeting was adjourned at 8:45 pm.